Genetic Counseling and Testing Programs*† for Hereditary ATTR (hATTR) Amyloidosis Offered at No Charge‡

A healthcare professional will help you determine if genetic testing through Alnylam Act® is the right choice for you.

*While program is sponsored by Alnylam Pharmaceuticals, all services are performed by independent third parties.
†Genetic testing is available in the US and certain other countries. Genetic counseling is available in the US.
‡To patients, healthcare professionals, or payers.
What is hATTR amyloidosis?
hATTR amyloidosis is a rare, inherited condition caused by a genetic variant, or change, in the TTR gene. This affects the function of a protein called transthyretin (TTR), which is made primarily in the liver and carries substances such as vitamin A. hATTR amyloidosis can affect multiple parts of the body, including the nerves, heart, and digestive system. An early diagnosis can help you better manage your symptoms and discuss the best plan with your doctor and family.

Who is at risk?
Although anyone can be at risk for this disease, it is more common for certain ethnicities, such as people of African, Portuguese, Irish, Brazilian, French, Japanese, and Swedish descent.

How is it diagnosed?
Diagnosis of hATTR amyloidosis involves various tests and procedures, but genetic testing can help confirm the diagnosis.

Why is family screening important?
hATTR amyloidosis is an inherited condition that is autosomal dominant, meaning that if one parent has hATTR amyloidosis, each child will have a 50% chance of inheriting the genetic variant that may cause the condition. A family member may inherit the TTR genetic variant, but that does not necessarily mean they will develop hATTR amyloidosis. A genetic test can help your family members determine their risk for hATTR amyloidosis.
How it works

1. Get started
   Ask a provider about genetic testing for hATTR amyloidosis through Alnylam Act®
   • Talk to your doctor or
   • Schedule a virtual visit with a genetic counselor

2. Pre-test genetic counseling (optional)*
   Speak with a genetic counselor to learn more about genetic testing

3. Provide a sample for genetic testing
   • Provide a sample using an Invitae sample collection kit (ask your doctor about sample collection options), or
   • Ask your doctor about the at-home specimen collection option offered by Invitae where you can collect a sample and send it back

4. Review results
   Results are ready in 10-21 days. They will be sent directly to your doctor for review

5. Post-test genetic counseling (optional)*
   Speak with a genetic counselor to review your test results and what they may mean for you and your family

*Genetic counseling available in the US. Genetic testing is available in the US and certain other countries. You may speak to a genetic counselor multiple times throughout the process, either before, during, or after genetic testing.

The Alnylam Act® program was created to provide access to genetic testing and counseling to patients as a way to help people make more informed decisions about their health.

• While Alnylam provides financial support for this program, tests and services are performed by independent third parties
• Healthcare professionals must confirm that patients meet certain criteria to use the program
• Alnylam receives de-identified patient data from this program, but at no time does Alnylam receive patient-identifiable information. Alnylam uses healthcare professional contact information for research and commercial purposes
• Genetic testing is available in the US and certain other countries. Genetic counseling is available in the US
• Healthcare professionals or patients who use this program have no obligation to recommend, purchase, order, prescribe, promote, administer, use, or support any Alnylam product
• No patients, healthcare professionals, or payers, including government payers, are billed for this program
Genetic testing process

If your doctor determines you are eligible, genetic testing is available through Invitae, a CLIA-certified independent genetic testing company.

1. Ask a healthcare professional to follow the instructions found at invitae.com/alnylam-act-ttr
2. Provide a DNA sample for genetic testing
3. Check back with your doctor within 10-21 days for your results

ASK YOUR DOCTOR about providing a sample from your home for testing.

Genetic counseling process

If you are considering a genetic test for hATTR amyloidosis, and you reside in the US, genetic counseling is available through InformedDNA, an independent genetic counseling company.

1. Call 1.888.475.3128 to schedule your appointment
2. Provide your doctor’s name, address, phone, and fax number or schedule an appointment with a genetic counselor
3. Talk to a genetic counselor about hATTR amyloidosis*

GENETIC COUNSELORS are able to help you understand the testing process and your results. Genetic counselors can also assist with family variant testing.

*A report will be sent directly to your doctor within 10-21 days.
Make more informed decisions about your health

Why is genetic testing important for hATTR amyloidosis?
Genetic testing can help identify your risk of hATTR amyloidosis by looking for a variant, or change, in the TTR gene. Genetic testing may also help to shorten the time to diagnosis and prevent misdiagnoses.

What is genetic counseling?
Genetic counseling through Alnylam Act® is available throughout the genetic testing process. Genetic counseling can help you and your family members learn more about hATTR amyloidosis and the chances of inheriting the disease, how testing works, and what may happen after a diagnosis.

How much does genetic testing and counseling cost through Alnylam Act®?
Alnylam Act® is a sponsored program, and the genetic testing and counseling services are offered to eligible patients at no charge.

Will any genetic or personal information be shared with Alnylam?
While Alnylam provides financial support for this program, at no time does Alnylam receive identifiable patient information. Third-party companies that support Alnylam Act® abide by HIPAA, the same standards doctors use to protect your information. Your information is safe and protected.

Talk with your healthcare professional today about genetic testing for hATTR amyloidosis